
Program Priorities of Crippled Children's Agencies: A Survey

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Synopsis

State Crippled Children's (CC) programs are known for their diversity in organization and varying coverage of diagnostic categories. Relatively little information is available concerning the programmatic priorities of CC agencies. To identify the activities central to the mission of State CC agencies, a survey was undertaken.

Results from the survey revealed considerable unanimity among CC directors in identifying activities deemed to be very important to their agencies' missions. However, CC program directors indicated that their agencies were unable to spend sufficient amounts of time working on many of these activities. With few exceptions, the same activities were accorded high priority regardless of the particular organizational type of CC program and regardless of the tenure of the director. Directors of CC programs were also consistent in identifying activities that were relatively less important to their agencies' missions, including activities related to community-based care.

Together with improvements in the treatment of childhood chronic illness, changes in the availability and financing of specialty medical care have substantially altered the problems that now face State CC programs. Despite major differences across the State CC programs, survey results reflect a broad consensus among CC directors concerning the current role of their agencies in the care of children with special health needs. Such a consensus may be an important element in gaining the additional resources needed to address current problems and to ensure high quality of care for these children and their families.

STATE CRIPPLED Children's (CC) programs have long been an important source of medical care for children with chronic handicapping conditions. Since their inception in 1935, these programs have evolved in response to changes in medical technology and in the organization and financing of services (1,2). In recognition of the changes in the population of children with chronic health problems, close to half of the States have replaced the words "crippled children" in their official designations with more current terms such as "special children's services" or "handicapped children's program." Several years ago Federal legislation formally changed the name of the national CC program to the Program for Children with Special Health Care Needs. According to available statistics, 49 CC agencies in the 57 States and Territories spent approximately \$400 million in 1983; 47 State agencies provided services to approximately 620,000 children (3).

State CC programs are known to be remarkably diverse in their organizational characteristics, the diagnostic conditions that they cover, and the services that they provide (4,5). Many States remain focused on a relatively narrow range of orthopedic and surgical conditions; others have expanded their eligibility criteria to include more medical illnesses; a few programs also cover children with chronic behavioral or developmental disorders. State CC programs also differ sharply in the way in which they interpret their legislative mandate, now contained in the Maternal and Child Health Services Block Grant of 1981 (6). Some States have pursued a policy of providing many services directly through CC clinics staffed by providers employed by the CC agency. In other States, a more conservative approach has prevailed, resulting in a program that is essentially a source of reimbursement for services rendered in the private sector on a fee-for-service basis. Table

Table 1. Types of service delivery systems of Crippled Children's (CC) programs

<i>Name</i>	<i>Service delivery location</i>	<i>Financing method</i>
Full vendor	Private office and public or private hospital	Only fee-for-service reimbursements.
Predominantly vendor	Private office and public or private hospital	Fee-for-service and some contractual reimbursements.
Contract clinic	CC clinic, private office, public or private hospital.	Clinic administrative staff and clinic providers under contract; all other services paid by fee-for-service reimbursements.
Clinic with vendors	CC clinic, private office, public or private hospital.	Clinic administrative staff directly employed by CC services; clinic providers and all other services paid by fee-for-service reimbursements.
Clinic with contracts	CC clinic, private office, public or private hospital.	Clinic administrative staff directly employed by CC services; clinic providers under contract; other services paid by fee-for-service reimbursement.
Predominantly provider	CC clinic, public or private hospital.	Clinic administrative staff and the majority of clinic providers employed directly by CC services; other services paid by fee-for-service or contractual reimbursements or both.
Full provider	CC clinic, CC hospital	Clinic administrative staff and clinic providers employed by CC services; hospital operated and staffed by CC services employees.

1, adapted from a previous review (7), illustrates the range of different approaches to delivering services that currently exist among State CC programs. It is important to stress that most programs are not purely one type; rather, most programs lean toward one system primarily and incorporate elements of others.

Another important difference, often overlooked, concerns the role of nurses in administering or providing services in CC programs. The most common approach is characterized by nurses who actively manage and participate in CC clinics; in some instances, these nurses are responsible for developing individual service plans for enrolled children as well as for ensuring that the families receive appropriate followup care. Many other arrangements have also evolved. For example, some States have developed relationships with public health nurses who make home visits or provide followup care to children in the CC program. A few States pay independent nursing agencies for services rendered under a prepaid per capita agreement or on a fee-for-service basis.

The American Academy of Pediatrics (8) has noted that the State CC programs "have provided years of needed experience in the development and testing of new and more effective methods of planning, organizing, and implementing community programs designed to bring health services of high quality to vulnerable children and youth." Indeed, the directors of State CC agencies have

accumulated considerable expertise in operating State programs for handicapped and chronically ill children. In light of the renewed emphasis on State control of health care programs, the collective wisdom of CC directors may be an important source of guidance for policy makers at every level concerned with the care of children with chronic illnesses and handicaps. The need for such guidance is pressing. As recent studies have shown, families of children with chronic health impairments face enduring, difficult problems in finding and paying for comprehensive health care of high quality (9). Moreover, the costs of care for many children whose lives depend on medical technology are increasing rapidly at a time when public and private funds for health care are diminishing. The role of State governments in ensuring adequate care for this population has become important.

Unfortunately, despite the 50-year history of the CC programs, few systematic studies of their characteristics or their functioning are available in the public health literature. In addition to the studies noted previously, there are available a series of historical accounts (10,11) and investigations of such specific issues as decision making (12) and costs of neonatal care (13) in CC programs. Recently, investigators noted the problems in availability of data for planning purposes (14). Overall, however, systematically collected information about the actual activities and priorities of State CC programs is sparse. What are the

Table 2. Ten activities most frequently judged very important by directors of Crippled Children's programs

Activity ¹	Judged very important		Judged not enough time allocated to activity	
	Number	Percent of total	Number	Percent of total
1. Coordinating patient care services (for example, phoning, setting up meetings)	33	73.3	16	36.4
2. Team conferencing on individual cases	31	68.9	27	61.4
3. Developing and disseminating standards of care . .	28	63.6	27	60.0
4. Reviewing or reworking eligibility criteria, or both . .	27	60.0	17	37.8
5. Collecting payments from public or private third-party payers, or both	27	60.0	13	29.5
6. Advocating with State legislators for additional funds	26	57.8	18	40.9
7. Developing or nurturing workable "linkages" with other governmental agencies	26	57.8	25	55.6
8. Developing prospective payment plans or other new ways of financing care	23	52.3	26	59.1
9. Developing or nurturing workable alliances with providers in the private sector	23	51.1	29	65.9
10. Continuing education for staff	21	46.7	35	77.8

¹ Total number of respondents across items varied from 44 to 45.

specific activities that CC program directors consider to be most important, and are their agencies able to allocate resources for these purposes? This study seeks to answer these questions.

Methods

In 1984, questionnaires were mailed to all State CC program directors. Followup letters and phone calls resulted in completed questionnaires from 46 States for a response rate of 92 percent. The questionnaire included a list of 27 specific activities that was developed in consultation with a variety of persons knowledgeable about CC programs. For each activity, the directors were asked to indicate how important the activity was in achieving the goals of the agency. Five importance ratings were possible, ranging from very important to very unimportant. In addition, for each activity, the directors were asked the following question: "How sufficient is the time that is currently being spent on this activity?" Four sufficiency-of-time ratings were possible: too much time, the right amount of time, not enough time, and not done.

It should be noted that most items were considered at least somewhat important by the majority of CC program directors, but comparatively few items were judged to be very important. Moreover, few items were judged to be very unimportant by any director, and there were only a few instances in which the rating of too much time was given. Hence, analyses of the results focused on the percentage of directors that gave ratings of very

important to each item. Percentages were calculated by dividing the number of directors who indicated that a particular activity was very important by the total number of directors who responded to the item.

Previous studies (4,7) suggested that the method of paying providers in CC programs is associated with selected outcome variables. Hence, the data were examined with the following questions in mind: Do directors of programs that pay physicians primarily on a fee-for-service basis identify different items as very important in comparison to directors of other types of programs (table 1)? Similarly, do programs that rely on nurses who are paid under salary or contractual arrangements have somewhat different priorities from other programs? It was anticipated that differences, if any, would be limited to activities relating to patient care and fiscal issues.

It is also plausible to hypothesize that priorities change with experience. Hence, the CC program directors were divided into three groups based on length of tenure as director. The three groups were those directors with (a) 1-3 years, (b) 4-6 years, and (c) 7 or more years of tenure. This breakdown was selected because it is likely to require at least 3 years to become familiar with the various aspects of directing a State program. Furthermore, contact with CC programs suggests that "veteran" directors (that is, those widely recognized for their experience) are typically those who have been in their positions for at least 7 years.

The survey responses were examined to deter-

Table 3. Percent of 3 tenure groups judging selected activities as very important

Priority	Years of tenure		
	1-3 (N = 18)	4-6 (N = 12)	7 or more (N = 13)
Developing workable alliances with providers in the private sector . . .	33	67	¹ 69
Developing and disseminating standards of care	41	¹ 83	77

¹ Significantly different from column 1 at $P \leq .05$.

mine whether the three groups varied in the items indicated to be very important. For both sets of questions (that is, those concerned with type of program and with tenure of director), analyses used the Z-test statistic for uncorrelated proportions; an alpha level of .05 was selected a priori as the cutoff point for determining significance (15).

Results

Table 2 lists the 10 activities that received the highest percentage of very important rankings. For each activity, the table notes the percentage of directors indicating that their agency did not spend enough time on the given activity. For example, 73 percent of the States judged "coordinating patient care services" as very important, yet more than one-third of the directors (36 percent) believed that their agency did not spend enough time on this activity. Ratings on the second most important activity, "team conferencing on individual cases," are even more striking: 69 percent of the directors believed this activity to be very important, but more than 60 percent indicated that their agency spends an insufficient amount of time doing it.

It is noteworthy that the first two activities concern patient care directly; the third- and fourth-rated activities involve public health aspects of the CC program (defining eligibility and setting standards); activities numbered 5, 6, and 8 concern financing; and activities 7 and 9 involve relationships with other institutions. It would appear that these domains were of special concern to CC directors at the time of the study.

In recent years, the Office of Maternal and Child Health of the Public Health Service has funded a yearly CC Institute in Columbus, OH, for persons in key leadership positions in State CC agencies. This institute (16) has addressed, in part,

the absence of continuing education opportunities for CC program staff. Continuing education received the 10th highest ranking in table 2 and was judged to be very important by almost 50 percent of the directors. However, 78 percent indicated that there was insufficient time for continuing education of staff. No other activity was judged to be more neglected than continuing education for staff.

Do programs with different organizational structures judge these 10 items differently? Analyses yielded only one significant difference at $P < .05$. In the 14 programs that directly employed or contracted with nurse providers, 86 percent ($N = 12$) of the directors indicated that team conferencing on individual cases was very important to the mission of the agency. In contrast, in the 28 programs that relied on other payment mechanisms for nurse providers, only 57 percent ($N = 16$) judged this item to be very important. Although it is possible that this single finding could have occurred by chance, it does raise the suggestion that team conferencing plays a greater role in programs that support nurses directly in the delivery of care in comparison to programs that rely on nurses supported by other mechanisms. Overall, however, the absence of major differences in program priorities between structurally diverse programs underscores a strong unanimity among directors in defining the core elements in the mission of a CC program.

Does the director's tenure make a difference? In 1984, of the 43 directors responding, 42 percent ($N = 18$) had been in their position for 1-3 years, 28 percent ($N = 12$) for 4-6 years, and 30 percent ($N = 13$) for 7 or more years. The analyses show that tenure has little effect on 8 of the top 10 priorities. However, on two activities, as tenure increased, a greater percentage of directors assigned ratings of very important.

These two activities, listed in table 3, were "developing workable alliances with providers in the private sector" and "developing and disseminating standards of care." It may be that directors new to their positions were concerned with matters internal to their organization and were able to turn their attention to more external issues only after several years of experience in their position. The additional experience may bring with it a greater appreciation of the importance of standard setting and of the relationship between the CC program and the private sector. Alternatively, of course, it may be that directors who have these priorities when they enter their position tend to remain in

Table 4. Other activities judged very important by directors of Crippled Children's programs

Activity ¹	Judged to be very important	
	Number	Percent
1. Meeting with advisory committee (or other policy review boards) about the program's policies and procedures.....	20	44.4
2. Review existing contracts with providers or hospitals or both.....	20	44.4
3. Developing written individual service plans.....	20	44.4
4. Reviewing recommendations for payments of existing authorizations (N = 40).....	16	40.0
5. Developing or disseminating guidelines for prior approval.....	16	35.6
6. Meeting with representatives of advocacy groups or voluntary organizations.....	14	31.1
7. Making site inspections at hospitals, clinics, or private offices (N = 43).....	12	27.9
8. Collecting copayments or pay-backs from parents.....	9	20.0
9. Providing continuing education programs for practicing pediatricians or other professional groups in private practice.....	7	15.6
10. Writing special service grants.....	7	15.6
11. Organizing screening programs in schools or communities (N = 44).....	5	11.4
12. Providing health care education programs for school teachers or personnel (N = 43).....	2	4.7
13. Consulting with regional or Federal officials regarding eligibility criteria (N = 43).....	2	4.7

¹ N = 45, unless otherwise indicated.

their jobs longer than those directors who do not.

Table 2 lists the 10 activities that were most frequently assigned a rating of very important. What activities were judged by relatively fewer CC directors to be very important? Table 4 provides an answer by listing additional activities and the number and percentage of directors judging each activity to be very important. The last two items in the table, including consulting with regional or Federal officials, received very important rankings from only 4.7 percent of the directors (N = 2). At least in terms of eligibility criteria, State directors rarely turn to Federal representatives for assistance. Outreach efforts aimed at schools, local practitioners, and communities (items 9, 11, and 12) were very important to only a few programs, suggesting that community-based efforts have not received the emphasis accorded to many other activities at the time of the survey.

Of all items listed in table 4, only one was deemed by a large majority of the directors to have insufficient attention devoted to it: 62.2 percent (N = 28) of the directors indicated that their agencies did not spend enough time meeting with representatives of advocacy groups or voluntary organizations. Even though only a comparatively few directors believed this activity was very important, many directors nevertheless believed that it warranted more time than was being devoted to it.

Discussion

For more than 50 years, Federal legislation has provided funds for CC agencies to "extend and

improve services" for children with chronic health problems. In the early years of the program—when specialty services for children with health impairments were largely unavailable in rural areas and poorly reimbursed in all locations—most CC programs directly provided or paid for the provision of specialty medical care. Over the last few decades, specialty medical services have become more generally available; rural areas are more likely to have access to specialty physicians or to rapid transport to tertiary care centers. Furthermore, public financing programs, such as Medicaid and the Supplemental Security Income program, have increased low-income families' utilization rates of all medical services (17).

The broadened availability of services and the improved financing of care have to some extent superseded the initial functions of State CC programs. With these developments, McPherson noted (18), "has come a need to de-emphasize the 'medical care' role of the State CC programs in providing or paying for selected 'eligible children' and to emphasize the 'public health' role of planning, promoting, and developing health services for all children with handicaps." The results of this survey suggest that CC programs are moving in this direction. Despite wide differences in the structure of their programs and the length of their tenure, State CC directors are remarkably consistent in identifying activities that are very important to their agencies' missions. More than two-thirds of all CC directors believe that coordination of care and team conferencing are or should be core elements of their programs.

The CC program is one of the few public health

care efforts in which the agency responsible for delivering or coordinating care is also responsible for ensuring the quality of that care. One of the historical roles for the CC, emphasized in the earliest publications describing the program (2,11), has been to establish standards of care. In 1978, the American Academy of Pediatrics formally recognized the contributions of CC programs in setting standards for the care of children with handicapping conditions (8). The importance of this activity remains high in the estimation of CC directors.

According to our results, CC program directors are concerned with issues of eligibility, financing, and relationships with other health care providers and agencies. These concerns are understandable in view of a major problem that faces almost every CC program: allocation of scarce resources in the context of enormous demand. Of the many potentially eligible children, who should be served first and how should these decisions be made? How can a program find additional funds? In what ways can a CC program work with other institutions, both public and private, to stretch collective resources? Such questions dominate the current agenda of CC program directors (4). The results of this survey confirm that many directors judge activities related to these concerns to be very important to the functioning of their agencies.

Results from this study are troublesome on several counts. Despite a broad consensus about important activities, CC program directors acknowledge that their agencies are unable to spend a sufficient amount of time working on some of these activities. For example, even though CC programs have a long history of concern with standards, 60 percent of the directors admit that their agencies allocate insufficient time for this activity; more than 60 percent indicate that team conferencing is relatively neglected. Continuing education, an important aspect in maintaining the quality of a staff, is believed to require more attention than it currently receives by directors who responded to that question. These statistics underscore either the absence of resources needed to accomplish many of the activities considered to be very important to the mission of the agency or the inability of directors to redirect existing resources through administrative decisions.

A second troubling result concerns the lack of emphasis on community-based efforts, such as reaching out to advocacy groups or providing continuing education for private practitioners and school teachers. The relative unimportance of these

activities to many CC agencies can be understood in light of a traditional emphasis on working with subspecialists in tertiary care settings. Yet several recent studies of children with handicaps and chronic illnesses have suggested that additional community-based services are needed to improve care substantially for these children and their families (9,19). In the years ahead, CC agencies may need to expand their mission in ways that more actively support services provided at the local level.

Results from this survey indicate that most CC directors, regardless of their tenure or the particular structure of their program, share relatively similar views about the core mission of a CC program. However, the resources available to fulfill the various aspects of this mission are often insufficient. Trends in service delivery arrangements toward capitation schemes and a growing emphasis on cost containment in health care may bode poorly for children with complex and special health needs (9,18). Yet, the unanimity among CC agency directors in defining core elements in the mission of their agencies can help counter the potential deterioration in the availability of needed services to this segment of children. A broad consensus concerning the role of a public agency may be the essential foundation for gaining the resources needed to ensure health care of high quality to chronically ill or handicapped children and their families.

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A Cost-Effectiveness Analysis of Self-Help Smoking Cessation Methods for Pregnant Women

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Synopsis.....

Estimates of the cost effectiveness and cost benefit of health promotion-health education methods for pregnant smokers designed to increase birth weight are not available. This paper presents the results of a cost-effectiveness analysis from a

recently completed randomized trial to evaluate the effectiveness of self-help smoking cessation methods for pregnant women in public health maternity clinics. The study population—309 pregnant smokers from 3 prenatal clinics—were randomly assigned, during their first clinic visit, to 1 of 3 groups: (a) group 1 received the standard clinic information and advice to quit smoking, (b) group 2 received the standard clinic information and advice to quit plus the manual "Freedom From Smoking in 20 Days" by the American Lung Association, and (c) group 3 received the standard clinic information and advice to quit plus the pregnancy-specific manual "A Pregnant Woman's Self-Help Guide to Quit Smoking."

The quit rates by the end of pregnancy were 2 percent for group 1, 6 percent for group 2, and 14 percent for group 3. Analyses also indicated that the method used for group 3 was the most cost effective: group 3 achieved smoking cessation at less than half the cost experienced by the other two groups.

Although additional studies are needed concerning the behavioral impact, cost effectiveness, and cost benefit of self-help health education methods for smoking cessation, the methods tested in this trial are promising as solutions to part of the problem of low birth weight among infants of smoking mothers in the United States.